Families with a Disabled Child's Perception of Societal Attitudes Towards Them

A. Zamkowska (Anna Zamkowska), M. Olszewski (Mikołaj Olszewski)

Original Article

Faculty of Philology and Pedagogy, University of Technology & Humanities in Radom, Poland.

E-mail address:

a.zamkowska@uthrad.pl

Reprint address:

Anna Zamkowska
Faculty of Philology and Pedagogy
University of Technology and Humanities in Radom
Malczewskiego 22
26-600 Radom
Poland

Abstract:

OBJECTIVE: The aim of the research was to investigate societal attitudes towards families with disabled children perceived by the parents of children with intellectual disabilities. DESIGN: Pilot study.
PARTICIPANTS: 110 parents, 75 mothers, 35 fathers of children with intellectual and complex disabilities.
METHODS: The survey questionnaire contained 30 statements devoted to affective, cognitive and behavioral components of an attitude.
RESULTS: In the parents' opinion: society experiences empathy; freedom in contact with these families; accepts them as guest and neighbors; their child's friend; recognizes their

ability to experience a joyful life; happiness; participation in social life; financial independence. can be empathic; recognizes their need of assistance. The only negative attitudes were perceiving families as demanding special privileges, experiencing difficulties in social situations and being easily offended.

CONCLUSION: The data shows that the majority of respondents recognize positive social attitudes towards families with disabled children both in affective and cognitive as well as behavioral aspects.

Introduction

Attitudes play an important role in social life. They significantly determine our response to social stimuli, feelings, as well as thoughts and behavior towards other people or groups (Bohner & Wanke, 2002). Both persons with disabilities and their families are particularly vulnerable to negative social attitudes expressed towards them. This is evidenced by a number of studies conducted in different countries (e.g. Staniland, 2009; Ostrowska, 2015, Barr & Bracchitta, 2012). This phenomenon, due to its severity, importance and negative consequences, has gained significance in the international arena, which has been reflected in a number of international declarations. One of the most influential, the *Convention on the Rights of Persons with Disabilities*, requires in Article 8 that "States that are party to the Convention to raise awareness throughout society regarding persons with disabilities and foster respect for the rights and dignity of disabled persons; combat stereotypes, prejudices and harmful practices relating to them, in all areas of life; and promote awareness of the capabilities and contributions of persons with disabilities" (UN, 2009). While acknowledging the correctness of the declarations made, it should be noted that both actions raising social awareness as well as research should be focused not only on the persons with disabilities, but also their families, as the family as a whole is affected by disability to some degree as well. However, researchers' attention to the issue of social attitudes has been focused so far mainly on the disabled persons themselves, both in the context of the purpose and the research tools (e.g. Antonak & Livneh, 2000; Findler *et al.,* 2017). The results of the pilot studies presented in this paper attempt to fill this gap aiming at determining how parents of children with intellectual disabilities perceive the social attitudes expressed towards them by members of society.

Attitudes towards persons with disabilities in theory

In the most commonly applied structural definition of an attitude, an attitude consists of three different components: affective (feelings manifested in relation to the subject of an attitude in a certain direction: positive - e.g. joy, respect, compassion or negative - e.g. fear or contempt); cognitive (information, knowledge and beliefs about the subject of attitude, suppositions, doubts); ; behavioral (intentional or real behavior towards the object of an attitude, which are a set of dispositions to behave in a specific way) (Smith, 1947). As emphasized by J. Turowski (1993), the above-mentioned components may appear in various proportions and combinations, but there are no attitudes without a cognitive component. Knowledge about the subject of an attitude may take the form of a certain stereotype (e.g. perception of people with disabilities), it may be false or may relate to a fictitious object.

H. Larkowa (1970) made a detailed list of social attitudes towards persons with disabilities distinguishing the following three categories:

– Emotional attitude: positive (kindness, liking), indirect (compassion, pity, indifference) and negative (reluctance to see disability);

– Volitional attitude: positive (acceptance and willingness to maintain contacts), indirect (watching) and negative (avoiding contact);

– Intellectual attitude: positive (recognition, respect), indirect (curiosity, interest), negative (negative assessment of person's features).

A.E. Sekowski (1994), divided attitudes towards the disabled into positive and negative ones and provided the following variables:

– positive attitudes determined by intellectual predisposition, reflectiveness, high self-esteem;

– Negative attitudes determined by low level of intelligence, low level of creative abilities, impulsiveness.

He believes that most of the manifested positive attitudes towards the disabled are in fact negative ones, often including an element of hostility. This view is confirmed by A. Ostrowska's (2015) research which showed that 60% of respondents exhibit ambivalent attitudes towards persons with disabilities, and another 15% display negative attitudes expressed through avoidance and isolation.

J. Granofsky (1955) presented a more detailed characteristic of positive and negative social attitudes towards the disabled. According to him, both positive and negative attitudes can be described in terms of 1) criterion for assessing the disabled person; 2) the cognitive criterion; 3) the criterion of emotional social interactions. The positive attitudes include: 1) objective and real assessment of the impact of disability on the psychosocial functioning of a disabled person as well as accepting and respecting her; 2) positive cognitive attitude assuming that a man, not his disability, is the subject of interest, expressed by knowing his needs and the level of meeting these needs, objectively perceiving his virtues, possibilities and achievements; 3) positive social behavior expressed by counteracting isolation, maintaining natural and friendly interpersonal contacts as well as integration with the disabled.

The negative social attitudes include such elements as: 1) feeling of pity or overprotection of the disabled, which are expressed by: underestimating, depreciating, overestimating the impact of disability on the psyche or exaggerating restrictions; 2) negative cognitive attitude, expressed by: excessive attention to the appearance of the disabled person; attention to disability; overestimation of the "ugliness" of disability; 3) negative social behavior - expressed by: increasing social distance; lack of acceptance for the participation of these persons in social contacts; a feeling of fear and embarrassment in their presence (Granofsky 1955).

Stigmatization is a highly unfavorable manifestation of negative attitudes towards people with disabilities. According to E. Jackowska (2009)[1], the concept of stigmatization refers to: the attitude of social disapproval, the pejorative reception of a specific group of people due to the physical or mental characteristics that distinguish this group from others; the system of values; lifestyle or other attributes. In relation to persons with disabilities, the concept of stigmatization includes several negative, interrelated and overlapping attitudes presented by society such as: distancing (avoiding entering into informal contacts); stereotyping; devaluation (disseminating negative, stereotypical opinions regarding them); delegitimization – (introducing legal restrictions on the possibility of sharing activity in some areas); segregation (blocking access to various forms of activity that are "reserved" for non-disabled). Stigmatization occurs when there are four components that make up this attitude:1) isolating what is different, like for example physical disability; labeling the person or people perceived as different; 2) attributing undesirable characteristics to labeled persons which reflect the stereotypes created earlier; 3) separating the group of labeled people ("them") from their own group ("us"); 4) labeled persons experience loss of status and discrimination, for example they are deprived of the right to employment, medical care; which entails both economic and social degradation.

A. Czyz (2013) claims that disabled people feel stigmatized by inappropriate social attitudes. This stigmatization results in a limitation or an inability to take up activity; leads to inhibition of self-development activities; hinders the achievement of life goals; blocks participation in cultural life. Disabled people through this social label cannot fully experience and enjoy the world around them. The quality of their lives is also negatively affected by the unsatisfactory quality of social contacts or inability to perform social roles which subsequently leads to low self-esteem, low self-confidence or low self-acceptance.

Attitudes towards persons with disabilities in research

Legal, economic, social and cultural factors have a crucial impact on the way in which society perceives persons with disabilities. In recent years

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[1] after E. Goffman, 1963 and B. G Link, J.C. Phelan (2001) conceptualization of stigma

in Poland, a dynamic transition can be noted from the predomination of the medical paradigm, focusing on individual deficits, to the social and biopsychosocial models focused on the inclusion discourse and functioning of a person with a disability in open society (Barnes & Mercer, 2004; Roulstone & Prideaux, 2012). This shift in paradigm brought about transformations in the area of law, education, economy and culture. It is therefore interesting to see how much it has changed the attitudes of society towards persons with disabilities in Poland. The comparison studies of A. Ostrowska held in 1993 and 2013 confirm their positive, but not complete change. In the study carried out in 1993 only 38% of respondents expressed a positive attitude towards people with disabilities, while in 2013 there was as much as 49% of positive responses. Unfortunately, in addition to a noted increase in empathy, compassion and understanding, there was also a decrease in offering specific help in various situations (Ostrowska, 2015). Moreover, an analysis of current research, including those researching the opinions of persons with disabilities as well, indicates that the main causes of difficulties and limitations they face every day are not only their physical or mental limitations, but also social responses to their disability (I. Wolska-Zogata 2012).

Similar experiences are shared by families with disabled persons. In her research, M. Kowalska - Kantyka (2006) tried to explain the factors determining the relationship between the environment and families raising children with disabilities. She compared the opinions of two cohorts: members of society and the disabled child's parents. Her study showed that most of the parents felt accepted by their immediate family, neighbors and relatives, only in the case of friends were the results unsatisfactory. The parents claimed factors such as unemployment, poverty, an inappropriate healthcare system, and ever-changing legal regulations as clear signs that the social environment is not truly interested in disabled persons. Parents also willingly talked about how they were treated in public places, in institutions, in their place of residence. These experiences cause them to experience bitterness and discouragement, and even lead to avoidance of contact with others. Slightly different conclusions can be drawn from the surveys conducted among society members, which show that society does not perceive them so negatively. The author explains the differences between parents' statements and survey results by the fact that parents most often talked about individual events and problematic situations that stuck in their memories and caused their emotional pain. The author also draws attention to the fact that parents are often hypersensitive and may misread social intentions and therefore avoid social contacts with others. They often prefer to isolate themselves and their children as a precaution, so that they do not experience disappointment or failure in the future.

Objectives and hypothesis

The study presented in this paper investigated society's attitudes towards families with disabled children in the perception of parents of children with intellectual disabilities. The researchers hypothesized that most parents perceive a positive social attitude towards them agreeing with statements describing positive attitudes of society members toward their families and disagreeing with the negative ones both in the affective and cognitive as well as the behavioral aspect of the analyzed attitudes.

Method

Participants

Parents were chosen randomly. A total 110 parents of children with disabilities took part in the survey: 75 were mothers (68%), 35 fathers (32%). All of the children had intellectual disabilities and some complex disabilities combined with autism (11%) or motor disabilities resulting from cerebral palsy and various genetic defects. 101 children attended special schools (76 children aged 3-10; 25 children 11-17 of age) and 9 were adults (age 18-26). The research was carried out in 2018 and 2019 in Poland: two special schools in medium-sized city Radom (N=94=85%) and one in large town Zyrardow (N=12=11%), as well as among 4 (4%) parents with adult children who had already graduated from special schools in Radom.

Instruments

An opinion survey, as one of the direct methods (Antonak & Livneh, 2000), was used to assess the perceived attitudes toward families with disabled children. It was based on the structural

definition of an attitude, J. Granofsky classification (1955) and R.J. Jones (1974) list of social contact types[2]. The survey questionnaire used for the study contained 30 statements. Respondents were asked to express their attitudes by responding to a list of questions about the referent, selecting one of the following responses: I agree, I do not agree, I have no opinion. The statements were devoted to three components:

1) the affective component:
   a. positive: sense of freedom in contact in a public place (7) and among close friends (2); desire to maintain close relationships (21); empathy (24);
   b. negative: pity (16), embarrassment (17), anxiety and fear (19);
2) Cognitive component:
   a. Positive: perceiving abilities: can take part in sport events (8), live among non-disabled (11), earn a living (12); enjoy life (27); be happy (30); contact is helpful to better meaning of life (20); should be more TV programs (22); there is no difference between families (25);
   b. Negative: perceiving luck of abilities: need mainly help (6), experience difficulties in bringing up children (9), come from disadvantaged background (10), want to be privileged (13), are unhappy (15), envy health (18), experience difficulties in social situations (23), are easily offended (28) and demanding (29);
3) Behavioral component:
   a. Positive: accepting the family in different social situations: as neighbor (1), guest at home (4), child's playground friend (3) and classmate (5); partaker in sports competitions for the disabled (26);
   b. Negative: avoidance as social contact is troublesome (14).
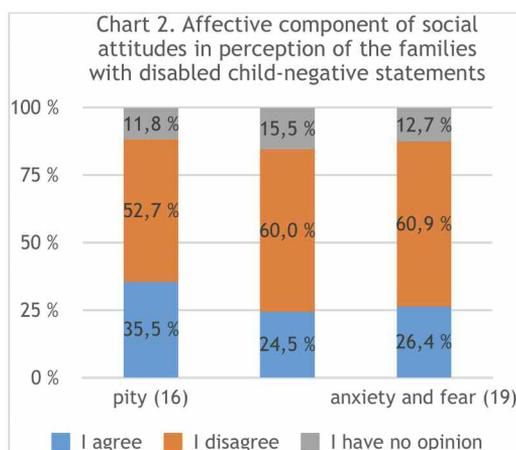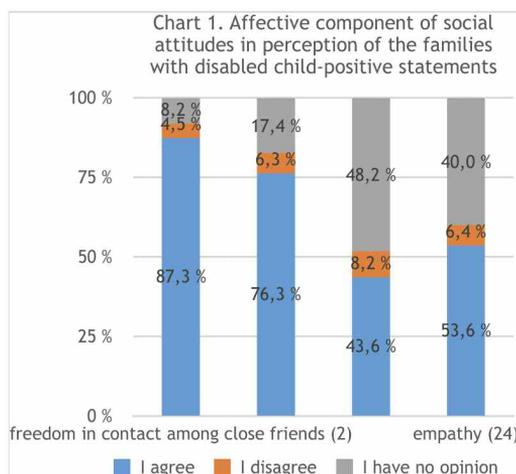
Results

The research conducted on a group of 110 parents of children with intellectual disabilities and intellectual disability combined with motor

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[2] R.J. Jones (1974) distinguished the types of contacts that non-disabled persons would be willing to make with people with disabilities, pointing to situations of acting as a spouse, a club colleague, a colleague, a close friend, a guest at home, a child's friend.

disability or autism concerned their perceptions of societal attitudes towards families with a disabled child. In assessing social attitudes, their three components were taken into account: affective, cognitive and behavioral ones.

Charts 1 and 2 present the parents' opinions on the affective component of societal attitudes towards families with a disabled child. The data shows that the majority of respondents agree that the members of society experience empathy (53.6%) and freedom in contact with these families in certain social situations like being together with close friends (87.3%) and meeting them in a public place (76.3%). Moreover, they do not agree with the experience that society expresses negative feelings such as pity towards them (52.7%), embarrassment (60.0%) or anxiety and fear (60.9%). Only when asked about members of society seeking close relations with families having disabled child, were the respondents'

Chart 1. Affective component of social attitudes in perception of the families with disabled child-positive statements

Chart 2. Affective component of social attitudes in perception of the families with disabled child-negative statements
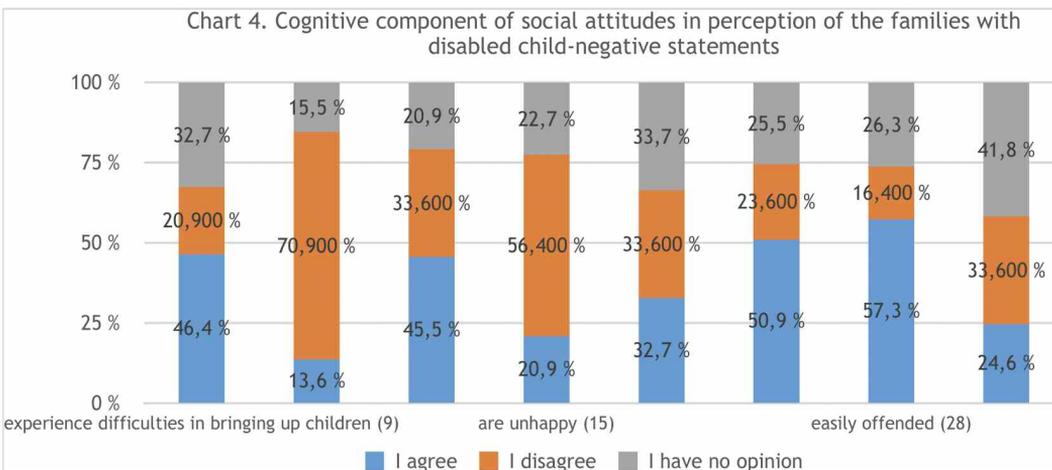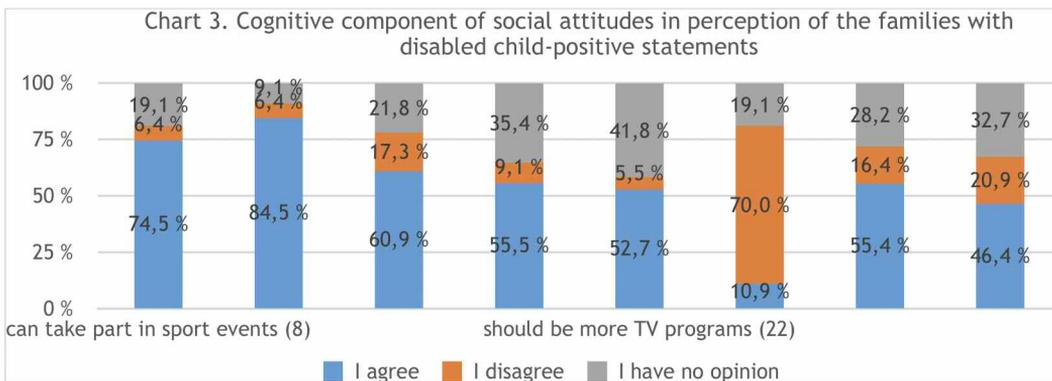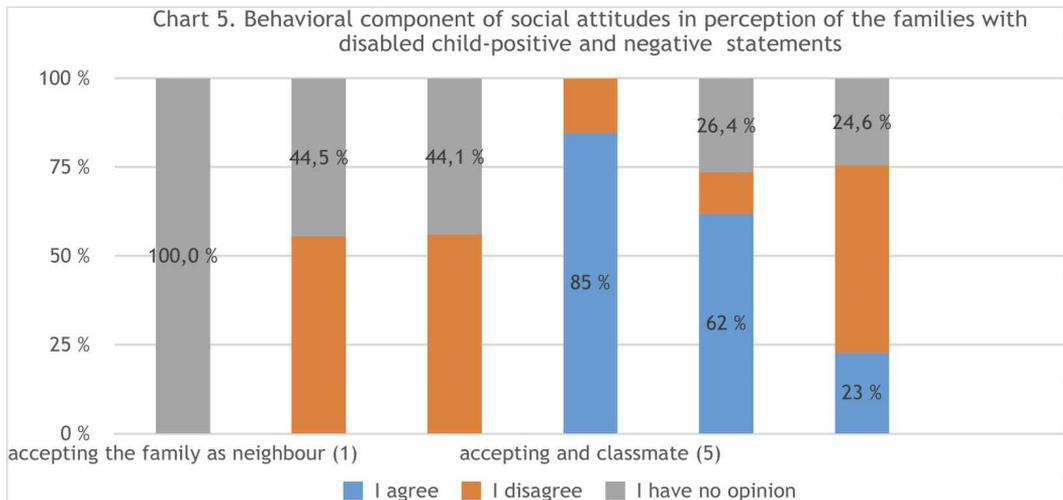
answers polarized, some did not have an opinion (48,2%) and some agreed with this statement (43,6%).

The following charts (3 and 4) present the results of research on the cognitive component of analyzed attitudes. The data shows that the majority of respondents agreed that society assesses the possibilities of families with disabled children to participate in social life in a positive and appropriate way (74.5%; 84.5%), earn their living (60.9%) and experience a joyful life (55,4%). In their opinion, society members (70.0%) do not see much difference between families with and without a disabled person. This does not mean that in their opinion a family with a disabled child does not require social support. On the contrary, most respondents (77.3%) stated that members of society perceive a family with a disabled person as needing assistance. Moreover, in the parents' opinion, the members of the public recognize the need to broadcast more TV programs about families with disabled children (52.7%) in order to broaden their knowledge about their abilities and needs. The respondents did not agree that society considers families with children with disabilities as coming from a disadvantaged background (70.9%) and as being unhappy (56.4%). However, some respondents pointed to the presence in social consciousness of some stereotypical assumptions, such as the desire of families with a disabled person to have special privileges (45.5%), experiencing difficulties in social situations (50.9%) and being easily offended (57.3%).

Chart 5 presents the results of research on the behavioral component of social attitudes. Their analysis shows that the majority of respondents attribute positive behavior towards their families displayed by the society by accepting them as their neighbor (87.3%), guest at their home (77.3%) as well as their child's playground friend (75.5%) and classmate (70.0%). Moreover, a small majority (52.7%) of respondents disagreed with the statement that society avoids contact with these families due to fear of embarrassment.

Chart 3. Cognitive component of social attitudes in perception of the families with disabled child-positive statements

Chart 4. Cognitive component of social attitudes in perception of the families with disabled child-negative statements

Chart 5. Behavioral component of social attitudes in perception of the families with disabled child-positive and negative statements

Discussion

The data shows that the majority of respondents recognize positive social attitudes towards families with disabled children in affective, cognitive and behavioral aspects. Society experiences empathy, freedom in contact with these families, is willing to accept them as guests and neighbors, as well as their child's playground friend and classmate. Pity, embarrassment, anxiety and fear are, in their opinion, much less represented in social attitudes. Society adequately and positively assesses the ability of families with disabled children to experience a joyful life, happiness, participation in social life, and financial independence. Members of society do not emphasize these families' otherness, rather they can be empathic and recognize their need of assistance. Despite this, there is, in the parents' opinion, a social need for further awareness of disability issues and its consequences. The only negative attitudes, indicated by the research, were the perception of the families as demanding special privileges, experiencing difficulties in social situations and being easily offended.

This finding agrees with M. Kowalska – Kantyka' (2006) research, which shows that parents experiencing barriers in accessing adequate medical and social assistance, as well as misunderstanding their child's needs and their own fears try to demand their rights and may become hypersensitive, which is perceived by society as a desire to obtain special privileges and that they are easily offended.

Conclusion

A family with a disabled child is an important part of the social space. As is clear from the comparative research cited in the article, many positive changes in the attitude of society towards these families can be observed. This is the result of the implementation of international conventions and a series of actions aimed at including disabled persons within the social space. Despite recognizing the positive changes, the parents with a disabled person who were surveyed attribute to society certain beliefs that have the character of negative stereotypes. In order to change them in public awareness, a number of long-term actions are required. It is therefore suggested to continue raising social awareness on disability and its effects on family life as well as to share common social activities with the disabled. (Yuker, 1994; Barr, Bracchitta, 2012; Bolt, 2016) This then creates an environment to develop a more realistic view of persons with disabilities and their families' experiences, needs and abilities and consequently more positive attitudes towards them.

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